

Effect of Psycho-Educational Program on Psychological Stress and Resilience Among Families Caring for Children with Intellectual Disability

Hoda Sayed Mohamed⁽¹⁾, Hossam Mohamed Elkhatib⁽²⁾, Neamat Mohamed Mohamed⁽³⁾

(1), (3) lecturer of Psychiatric, Mental Health Nursing, Faculty of Nursing, Ain Shams University

(2) Lecturer of psychiatry faculty of medicine, Misr University for science and technology

ABSTRACT

Background: Family caring for children with Intellectual Disability tend to report higher rates of psychological stress which impacts their ability to meet their child's needs. So, the family needs to remain resilient in the face of significant stress in their lives. **Aim.** This study aimed to investigate the effect of the psycho-educational program on psychological stress and resilience among family caregivers of children with intellectual disabilities. **Research design:** A quasi-experimental research design was used in this study. **Subjects.** The study subjects consisted of 70 family caregivers of children with intellectual disabilities. **Setting:** The study was conducted at the child psychiatric outpatient clinic of Al Abbassia mental health hospital. **Tools:** The data was collected using 1) An interview questionnaire to assess sociodemographic characteristics of family caregivers and their children 2) Psychological Stress Scale. 3) Resilience scale to measure resilience among family caregivers of children with intellectual disability. **Results:** There was a highly statistically significant difference observed pre-and post-program implementation regarding the total level of psychological stress among family caregivers understudy, where preprogram implementation, more than three-fifths of subjects under study (62.9%) had a severe level of psychological stress, meanwhile, a small minority of them reported sever degree of psychological stress in the post-program implementation phase, representing 12.9%. Also, there was a remarkable improvement in the total level of resilience among family caregivers understudy post-program implementation, where more than two-thirds of them (70%) had a low level of resilience preprogram, and 5.8% of them only reported a low level of resilience post-program implementation. **Conclusions.** The total level of psychological stress has been decreased post- psychoeducational program implementation compared to the pre-program implementation and there was a remarkable improvement also in the level of resilience post-program implementation compared to the pre-program implementation. **Recommendations.** This study recommended that a counseling clinic should be established for all family caregivers caring for children with intellectual disabilities to offer appropriate information and psychological support and guide them to know how to deal with their child's problems to decrease stress and improve resilience.

Keywords: Intellectual disability, Family Caregivers, Resilience, Children, Psychological Stress, Psycho-Educational program

Introduction

Family caring for children with intellectual disabilities (ID) tend to report higher than average rates of psychological stress. Chronic psychological distress may place the family at increased risk of marital disruption, family dysfunction, and several physical and mental health conditions (Alsharaydeh, Alqudah, Lee, & Chan, 2019). World Health Organization, 2007 defined Intellectual disabilities as a condition of arrested or incomplete development of mind, which is especially characterized by impairment of skills manifested during the

developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities. Moreover, Intellectual disabilities among children were described by Bhaumik, & Alexander, 2020, as serious changes in the way children typically learn, behave or handle their emotions which cause distress and problems getting through the day. ID was also defined by Wakimizu, Fujioka, Nishigaki, & Matsuzawa, 2018 as the impairment of cognitive functioning characterized by having an IQ less than 70 from the total of 100. it's also characterized by impairment in adaptive functioning where individuals experience

general learning challenges and may take a long time to develop social and practical skills.

According to Edition (2013), intellectual disabilities includes, learning disabilities, Down syndrome, mental retardations, cerebral palsy, fragile X syndrome, Prader Willi Syndrome (PWS), fetal alcohol spectrum (FAS), Clinically, intellectual disability is a subtype of cognitive deficit or disability affecting intellectual abilities, which is a broader concept and includes intellectual deficits that are too mild to properly qualify as intellectual disability, or too specific (as in specific learning disability), or acquired later in life through acquired brain injuries or neurodegenerative diseases like dementia. Cognitive deficits may appear at any age (**McConnell & Savage, 2015**). Developmental disability is any disability that is due to problems with growth and development. This term encompasses many congenital medical conditions that have no mental or intellectual components, (**Lee, Cascella, & Marwaha, 2019**).

According to **Patton et al, (2018)**, caring for children with intellectual disabilities increase the risk of physical health conditions that are etiologically associated with chronic stress such as obesity, cardiovascular diseases, autoimmune diseases, and gastrointestinal disorders. chronic stress may also increase the risk of marital disruption and family breakdown or dysfunction e.g., low cohesion, emotional withdrawal, relationship conflict, and child maltreatment. Furthermore, **Hassanzadeh, & Hojjati, (2017)** noticed that several studies have found that child behavior problems predict latter parent stress, which affects family cohesion and marital satisfaction leading to leading to more parent-child interaction which intern predicts child behavior problems.

Also, Boat, & Nasem, (2015) illustrated that parents of children with mental disabilities devote considerably more time than parents of typically developing children tasks. In addition, families having a child with intellectual disability may invest considerable time and energy in the challenging process of accessing and investigating support. Services discontinuity of accessing and navigating

supports. Services discontinue place a strain on families of children with disabilities and then there is the expectation that families will invest considerable time, energy, and financial resources in the amelioration of their child's impairment (keeping appointments with healthcare professionals, implementing home programs, so they need to be resilient to be able to cope with these stressors. (**Caldwell, Jones, Gallus, & Henry, 2018**)

Resilience was operationally defined by **Blacher & Baker (2019)** as family life congruence (i.e. The extent to which the daily routine was congruent with the family values, goals, needs, and interests of family members. Also, **Masulani et al. (2016)** defined resilience as characteristics, dimensions, and properties that help families to be resistant to disruption in the face of change and adaptive in the face of crises. Moreover, resilience among families of children with mental disabilities is implicitly defined by **Henry, et al. (2018)**, as the absence of psychological distress and normal family functioning. Families demonstrate resilience when adaptive adversity, they are competent in performing one or more of the core family functions including membership and family formation, economic support, nurturance, education, socialization, and protection of venerable members **Currie, & Szabo, (2020)**.

Moreover, **Ashori, Norouzi, & Jalil-Abkenar, (2019)** identified three empirically supported resilience factors involve; dispositional optimism, problem-focused coping (including positive reappraisal), and social support. Dispositional optimism is the tendency to look for positive and expected positive outcomes when confronting problems in life to prevent stressful situations from recurring. The third factor; is social support which improves the feeling of belonging and act as a stress buffer on parent and families' wellbeing.

In this context, **Oh, & Chang, 2014** proposed that a Psychoeducational intervention program should be conducted to modify or reform the child, caregivers, and/or family stressors and assist them to adapt to everyday challenges related to the care of children with intellectual disabilities and enable them to access to treatment resources they need to

successfully juggle work and family demands such as meaningful and flexible employment and affordable childcare options, management of resources needed to meet the normal daily hassles associated with psychological distress and family dysfunction to improve adaptive challenges and contributed to resilience. In addition, **Miranda, et al (2019)** illustrated that parents of children with intellectual disabilities need to be trained on cognitive behavioral skills to resume their daily routine activities involving employment-related activities, family leisure time, development of healthy lifestyle, and practice stress reduction techniques, social skills training i.e. time management, problem-solving, social interaction, etc.

Significance of the Study:

Globally, the prevalence of intellectual disability has been estimated by the **American Academy of Pediatrics, (2016)** to be approximately 16.4/1000 persons in low-income countries, approximately 15.94/1000 for middle-income countries, and approximately 9.21/1000 in high-income countries. Overall, intellectual disability occurs more in boys than in girls: 2:1 in mild intellectual disability and 1.5: 1 in severe intellectual disability. In part, this may be a consequence of the many X-linked disorders associated with intellectual disability, the most prominent being Down and fragile X syndrome.

Caregivers of children with intellectual disability (ID) tend to report higher rates of stress. Chronic psychological distress may place parents at increased risk of family dysfunction, and for several physical and mental health conditions. Intervention studies offer a potentially powerful means of testing ideas about the underlying mechanisms or causes of psychological distress and dysfunction among families of children with mental disabilities (**Hsiao, 2014; and Rajan, & John, 2017**).

So psychoeducational intervention program that effectively ameliorates behavior problems and/or equips the family with effective coping strategies should reduce psychological distress family dysfunction and improve family resilience. Hence, the

development and implementation of a psychoeducational program become an important element of psychiatric nursing interventions to minimize psychological stress and improve resilience among families caregivers of children with intellectual disabilities.

Aim of the Study:

The current study aimed to investigate the effect of the psycho-educational program on psychological stress and resilience among families caregivers of children with intellectual disabilities.

This aim was achieved through:

- 1) Assessing the levels of stress among families caring for children with intellectual disabilities.
- 2) Assessing the levels of resilience among families caring for children with intellectual disabilities.
- 3) Accordingly, developing and implementing a psycho-educational program to minimize psychological stress and enhance resilience among families caring for children with intellectual disabilities.
- 4) Evaluating the effect of the psycho-educational program on psychological stress and resilience among families caring for children with intellectual disability.

Research Hypothesis:

- 1) Psychoeducational program for families caring for children with intellectual disabilities will minimize the psychological stress resulting from caring for their children. with intellectual disabilities
- 2) Psychoeducational program for families caring for children with intellectual disabilities will improve resilience in caring for their children with intellectual disabilities.

Subjects and Methods

Research design

A quasi-experimental (single group pre/posttest) design was used to investigate the effect of the psycho-educational Program on Psychological stress and resilience among

families caring for children with intellectual disabilities.

Subjects:

A purposive sample of **70** families caregivers who completed the intervention program out of **102** families caring for children with intellectual disabilities was obtained during the study period based on specific inclusion criteria.

Study setting:

The present study was conducted in child psychiatry at outpatient clinics of El Abbassia mental health hospital from January to June 2019. The study population was composed of family caregivers of children with intellectual disabilities who receive treatment and follow up services in the above-mentioned setting on 3 days per week (Saturday, Monday & Thursday) from 8 am to 2 pm, the child psychiatric outpatients clinics composed of two buildings and contain 9 daytime examination clinics for the treatment of children with mental disorders and mental disabilities

Inclusion Criteria:

- Age of caregivers: 18-65 years
- Able to read and write
- Written consent for participation in the study.
- Direct family caregivers for children with intellectual disabilities (children below 18 years)
- Free from psychotic disorders or substance use disorders.

Data Collection Tools:

The data was collected using a self-administered questionnaire that included Three sections as follows

- 1) **The first section: Socio-demographic data sheet:** It contains two parts (1) Data pertinent by caregivers' age, sex, degree of relativeness to the children with disability, marital status, level of education, working status, monthly income, and the number of children with intellectual disability. (2) History of intellectual disability as the age of the cared child, child sex, type of

intellectual disability, duration of Childs's disability, and degree of child disability.

- 2) **The Second Section: Psychological Stress for Parents of Handicapped Scale:** It has been originally developed by **Al-Sartawi& Al-Shakhs (1998)** in Arabic language to assess the level of stress among mothers of children with intellectual disabilities and modified by the researchers to accommodate the current study. Psychological Stress Scale has **(80)** items rated on five-point Likert Scale (Never occur: one degree, rarely occur: two degrees, sometimes: three degrees, often: four degrees, always occur: five degrees)

Psychological Stress for Parents of Handicapped Scale has Seven Dimensions including:

- 1) Psychological and organic symptoms (12 items).
- 2) Feelings of despair and frustration (11 items).
- 3) Cognitive and psychological problems of the child (7 items).
- 4) Family and social problems (14 items)
- 5) Embarrassment about the future of the child (9 items).
- 6) Problems of Independence performance of the child (10 items).
- 7) Inability to tolerate meeting the child's needs (17 items).

The total score ranged from (80-to 400), and the level of stress was categorized into the following mean scores:

- <80 (No Stress)
- 80 .1-186 (Mild Stress)
- 186.1 – 293.1 (Moderate stress)
- 293.2 -400 (Severe Stress)

The internal reliability of the scale is ranged from 0.917 to 0.939 and **the content validity** is 0.96 as rated by families caregivers understudy which is considered significantly high, Coefficient given was 8.9. The psychological stress Scale can be completed within 10-15 minutes.

3) The Third Section: Resilience Scale for Arbitration: This scale was originally developed by **Abou-Dagga (2013)** in the Arabic language to assess the domains of resilience among family caregivers of children with intellectual disabilities through three subscales includes:

1. Individual subscale (34 items)
2. Family subscale (8 items).
3. Community subscale (13 items).

Resilience Scale contains a total of 55 items representing the elements of resilience using a five-point Likert scale which ranged from 1 (Strongly Disagree), 2 (Disagree), 3 (Uncertain), 4 (Agree), and 5 (Strongly Agree). The resilience Scale can be completed within (15-20 minutes). The total score ranged from 55-to 275 where the higher score indicates a higher resilience rate in each subscale

Content Validity of the questionnaire with family caregivers of children with mental disabilities was made and tested to its correlation coefficient between total subscales were 0.87, 0.91, and 0.85 respectively. **The reliability** of the scale was evaluated through a test-retest approach and internal consistency. Cronbach alpha of all domains was 0.87 which reflected good internal consistency reliability of the tool. There was a highly statistically significant correlation between all domains of quality of life ($P < 0.001$).

Operational Design

The operational design for this study included the preparatory phase, pilot study, fieldwork, ethical considerations

Preparatory phase:

It included reviewing past, current, local, and international related literature, and theoretical knowledge of intellectual disability, psychological stress, and resilience among families caring for children with intellectual disabilities using books, articles, periodicals, and other available resources through the Internet search. The researchers modified the standardized tools to accommodate the current study.

Pilot Study: A pilot study was carried out on (7) family caregivers representing around 10%

of the total sample before conducting the actual study to ensure clarity of the questions, validity, and applicability of data collection tools, and time needed to complete them. All subjects who were involved in the pilot study were excluded from the main study sample. The tool was finalized based on the results of the pilot study.

Fieldwork:

- The psychoeducational program implementation consumed six successive months for all program phases (pre-program assessment, program implementation, and post-program evaluation). It began during the period from January to June 2019. The researchers visited the selected setting 3 days per week (Saturday, Monday & Thursday) from 8 am to 12 pm to implement the psycho-educational program. The researchers met with each family caregiver individually and introduced themselves; explained the purpose and nature of the study; and ensured the confidentiality of data. Caregivers were asked if they were interested and agreed to participate in the study. After that, the questionnaire forms were distributed to each caregiver individually and they were asked to complete it by selecting only one response that reflects the actual situation. The researchers asked the family caregivers about any difficulties that faced them during answering the questionnaires and offered help. The questionnaires took about (30-45) minutes.
- Based on the assessment findings, the psycho-educational program was developed by the researchers and revised by a specialized psychiatrist and professor of psychiatric/mental health nurse before its application to the family caregivers of children with intellectual disabilities.
- For the implementation of the psychiatric nursing intervention program, The caregivers were integrated into six subgroups, each group consists of 11-12 members, three groups on Saturday, one group on Monday, and two groups on Thursday according to the agreed time

between the researchers and the group members which range between 8 am -2 pm, each group received a total of 20 training session (3 theoretical sessions and 17 practical sessions), each session took from 45 minutes up to one hour during their follow-up visit.

- Approaches that the researchers follow during the sessions (Leaving them expressing feelings freely, listening attentively to every subject, controlling the session, encouragement, and involvement, constructive criticism and appraisal of achievement, encouraging speaking, or stopping speaking to listen without interruption).
- The researchers informed the participants that their progress, home assignments, and any faced difficulties will be followed up through phone contact until the next meeting. Post-test was done at the period from the beginning of the first week of June to the last week of June 201

Contents of the psychoeducational program

Psycho-educational Program conducted on **20 sessions** divided into two main parts:

Part I: Introductory & Theoretical Part (3 sessions).

This part Includes an introductory session, orientation about the aim of the psycho-educational program, and general information about intellectual disabilities as meaning, types, characteristics, causes, and impact of caregiving role on family life.

Part II: Practical Training Part (17 sessions):

The practical part of this psycho-educational program was used to help family caregivers of children with intellectual disabilities to deal with their psychological stress and improve their resilience through the following Psychoeducational sessions

- 1) Management of children's behavioral problems; establishing routines and house rules, positive discipline, practicing positive behavior management skills, including praise, ignoring, teaching good

behaviors, methods for diverting child attention (**2 sessions**).

- 2) Control of emotions, behaviors, and stressful situations (**2 sessions**).
- 3) Sources of stress among families caring for children with intellectual disability (**2 sessions**)
- 4) Psychoeducation about stress reduction methods include changing thoughts, deep breathing exercises, living with child disability, leisure time dealing with anger (**4 sessions**)
- 5) Psychoeducation about practicing a healthy lifestyle includes eating a complete balanced diet, getting a restful sleeping, physical exercise (**2 sessions**)
- 6) Resilience development (meaning of resilience, ways of developing resilience, how to deal with difficult situations, how to solve problems, overcome negative emotions, and how to think positively (**4 sessions**))
- 7) Review all the program contents and filling post-test interview questionnaires (**1session**)

Ethical Considerations:

At the initial interview, each caregiver was informed about the aim and nature of the study, and the researchers emphasized that participation would be voluntary; hence every caregiver had the right to participate or refuse participation, to be included in the work, and they were informed about the right to withdraw at any time without giving any reasons, and without any consequences. The consent for participation was taken written. In addition, the confidentiality of any gathered data was assured, explained, and printed in the data collection tools.

Administrative Design

An official letter was issued from the Dean of faculty of nursing, Ain Shams University, to the director of the child psychiatry at outpatient clinics of El Abbassia mental health hospital explaining the aim of the study and requesting their permission for data collection.

Statistical Analysis:

Data entry and statistical analysis were done using the computer software for excel program and statistical package for social science SPSS version 20.0. Data were presented using descriptive statistics in the form of frequencies and percentages for the categorical data. Continuous variables were summarized as means and standard deviations (SD), paired sample t. test and Pearson correlation. Statistical significance was considered at a p-value <0.05 was used to identify the significance in a group before and after psycho-educational program implementation, the significant value was set at ≤ 0.05

Results:

Table (1) Revealed that the mean age of the family caregiver's understudy was 33.34 ± 9.43 . The majority of them (90%) were females; 84.2% were mothers of children with intellectual disabilities, and most of the sample (90%) were married. Regarding educational level, more than two-thirds of them (68.6 %) were able to read and write. In addition, most of the studied sample didn't work and had not enough monthly income representing 83%, and 88.6 % respectively. Moreover, this table represents that a small minority of family caregiver understudy (8.6%) had more than one child with an intellectual disability.

Table (2) Displayed the history of intellectual disabilities among children under study. The table represented that the mean age of children understudy was 10.24 ± 3.06 , more than three-quarters of them (77.6%) were male, and more than one-third (36.8%) of them were diagnosed with mental retardation. Regarding the duration of child disability, (48.7%) of children under stud had a duration of intellectual disability ranging from 5 to 10 years, and nearly three-fifths of them (59.2%) had a severe degree of intellectual disability.

Table (3) Indicated that there was a statistically significant improvement regarding types of family caregiver's stress mean score in

the post-program implementation phase compared to the preprogram phase, including psychological and organic symptoms, feelings of despair and frustration, cognitive and psychological problems of the child, family, and social problems ($p < 0.05$).

Figure (1): Revealed that there was a highly statistically significant difference observed pre-and post-program implementation regarding the total level of psychological stress among family caregivers understudy, where preprogram implementation, more than three-fifths of subjects under study (62.9%) had a severe level of psychological stress, meanwhile, a small minority of them reported sever degree of psychological stress in the post-program implementation phase, representing (12.9%).

Table (4) Indicated that there was a highly statistically significant difference between the resilience subscale among family caregivers of children with intellectual disabilities including individual, family, and community dimensions of resilience ($P < .001$)

Figure (2): Showed that there was a remarkable improvement in the total level of resilience among family caregivers understudy post-program implementation phase compared to the preprogrammed level, where more than two-thirds of them (70%) had a low level of resilience preprogram, meanwhile, 5.8% of them reported a low level of resilience post-program implementation.

As shown in **Table (5)** there was a moderate negative correlation between the total level of psychological stress and the level of resilience preprogram implementation. Meanwhile, there was a high negative correlation between the total level of psychological stress and the level of resilience after program implementation. In addition, there was a high negative correlation between feelings of despair and frustration subscale, inability to tolerate meeting of the child's needs, and individual resilience pre-and post-program implementation ($P < 0.001$).

Table (1): Frequency and percentage distribution of the family caring for children with intellectual disability understudy according to their socio-demographic characteristics (n=70):

Items	Family Caregivers	
	No.	%
Age (Years):		
18- <30	11	15.8
30- < 40	36	51.4
40 years or more	23	32.8
Mean \pm SD	(33.34 \pm 9.43)	
Sex:		
Male	7	10
Female	63	90
Degree of relativeness between the child and his caregiver:		
Mother	59	84.2
Father	4	5.7
Sister	3	4.3
Brother	2	2.9
Second Degree Relatives	2	2.9
Marital Status:		
Married	63	90
Single	4	5.7
Divorced/separated	3	4.3
Level of Education:		
Read & Write	48	68.6
Primary Education	13	18.6
secondary Education	7	10
University education	2	2.8
Occupational Level:		
Working	12	17
Not working	58	83
Monthly Income:		
Not enough	62	88.6
Enough	8	11.4
Numbers of children with intellectual disabilities:		
One child	64	91.4
More than one child	6	8.6

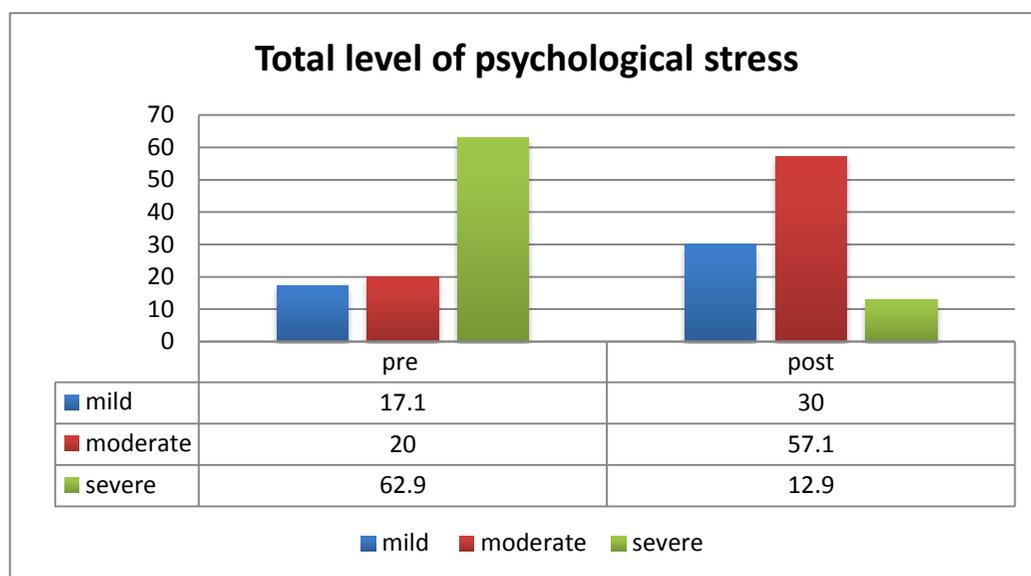
Table (2): Frequency and percentage distribution of children under study according to their history of intellectual disability (N=76 children for 70 family caregivers)

Items	Children with disability (n=76)	
	No.	%
Age of children with intellectual disabilities:		
3 -5 years	13	17.1
5-12 years	47	61.8
12-18 years	16	21.1
Mean \pmSD	10.24 \pm 3.06	
Children's sex:		
Male	59	77.6
Female	17	22.4
Type of intellectual disabilities:		
Learning disabilities	19	25
Down syndrome	21	27.6
Mental retardation	28	36.8
Fragile X syndrome	6	7.9
Prader-Willi Syndrome (PWS)	2	2.6
Duration of child's disability:		
Less than one year	11	14.5
1-> 5 years	21	27.6
5-> 10 years	37	48.7
+ 10 years	7	9.2
Degree of intellectual disability		
Mild	13	17.1
Moderate	18	23.7
Severe	45	59.2

Table (3): Distribution of studied family caregivers of children with an intellectual disability regarding types of family caregiver's stressors mean score pre-and post-program implementation (N=70):

Psychological stress Domains	Family Caregivers (N=70)				T-test	P-value
	Pre-Program		Post Program			
	Mean	SD	Mean	SD		
Psychological and organic symptoms	44.3	0.63	28.7	3.45	7.34	0.03*
Feelings of despair and frustration	38.2	1.61	25.6	1.87	6.41	0.01**
Cognitive and psychological problems of the child	25.3	0.32	16.2	0.43	8.0	0.04*
Family and social problems.	38.6	2.57	31.3	1.12	11.22	0.05*
Embarrassment about the future of the child.	39.4	5.94	31.2	2.56	7.45	0.14
Problems of Independence performance of the child.	27.9	3.16	21.2	1.43	6.55	0.11
Inability to tolerate meeting the child's needs.	48.9	7.59	31.7	3.87	6.67	0.01**

(*) Statistically significant at $p < 0.05$, (**) Statistically highly significant at $p < 0.001$, Non-Significant at $p > 0.05$

**Figure (1):** Comparison of the total level of caregivers' psychological stress pre and post-program implementation (N=70)**Table (4):** Distribution of studied family caregivers of children with an intellectual disability regarding their resilience subscale pre-and post-program implementation (N=70)

Resilience Subscales	Family Caregivers (N=70)				p-value
	Pre-Program		Post Program		
	Mean	SD	Mean	SD	
Individual subscale	66.8	11.65	112.45	16.65	0.01**
Family subscale	18.2	5.91	27.77	10.76	0.01**
Community subscale	29.6	19.34	39.98	10.87	0.01**
Total	114.6	36.9	180.2	38.19	0.01**

(*) Statistically significant at $p < 0.05$, (**) Statistically highly significant at $p < 0.001$, Non-Significant at $p > 0.05$

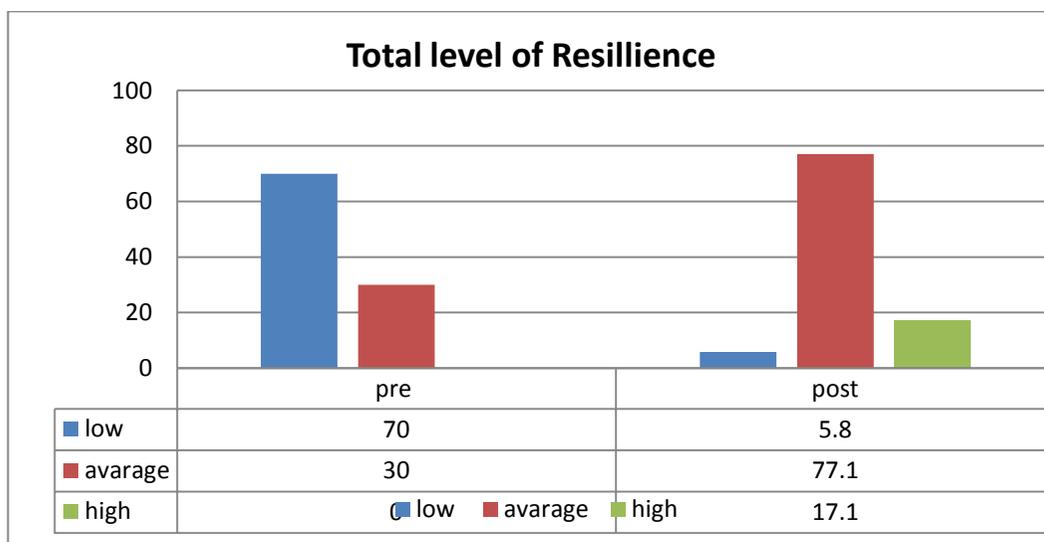


Figure (2): Comparison of the total level of caregivers’ resilience pre and post-program implementation (n=70).

Table (5): Correlation between psychological stress and resilience among family caregivers of children with intellectual disabilities pre and post-program implementation (n=70).

Psychological stress Domains	Resilience Subscales Among Family Caregivers of Children with Intellectual Disabilities (n=70)							
	Pre				Post			
	Individual	Family	community	Total	Individual	Family	community	Total
Psychological and organic symptoms	-.345	-.656	-.652	-.365	-.651	-.652	-.365	-.651
Feelings of despair and frustration	-.712*	-.365	-.651	-.662*	-.771*	-.365	-.651	-.783*
Cognitive and psychological problems of the child	-.365	-.651	-.552	-.365	-.487	-.365	-.651	-.652
Family and social problems.	-.364	-.536*	-.345	-.589*	-.578	-.592*	-.656	-.797*
Embarrassment about the future of the child.	-.345	-.479*	-.365	-.676*	-.652	-.335	-.651	-.652
Problems of Independence performance of the child.	-.656	-.656	-.654	-.383	-.475	-.486*	-.365	-.651
Inability to tolerate meeting the child’s needs.	-.831*	-.365	-.651	-.352	-.698*	-.659	-.658	-.801*
Total	-.365	-.451	-.652	-.493*	-.564	-.365	-.651	-.712*

(*) Statistically significant at $p < 0.05$, (**) Statistically highly significant at $p < 0.001$, Non-Significant at $p > 0.05$

Discussion:

Taking care of children with an intellectual disability creates chronic stress for family caregivers over a long period. The continuous intensive caregiving that the parents must provide hurts the level of personal stress and resilience (Henry, Hubbard,

Struckmeyer, & Spencer, 2018). The present study aimed to investigate the effect of the psycho-educational program on psychological stress and resilience among families caregivers of children with intellectual disabilities.

Regarding socio-demographic characteristics of family caregivers understudy,

the present study results revealed that the majority of family caregivers of children with intellectual disabilities understudy were females. It can be attributed to the high sense of responsibility, self-sacrifice, and obligations of females toward their family members as the main source of care and compassion in the family, especially during their middle age where they did their maximum efforts to protect their family members and maintain their wellbeing. This study finding was agreed with the finding of **Al-Krenawi, Graham, & Al Gharaibeh (2011)**, who explained that mothers more anxious about the future of their child than fathers; due to increasing cohesion and integrity with family and difficulty to separate from their child that usually associated with a higher level of psychological stress. These study results were also agreed by **Henry, Hubbard, Struckmeyer & Spencer (2018)**, who found that mothers experienced a greater caregiving burden when compared with fathers, mothers were significantly more stressed, more involved, and reported higher levels of stress and coping related to caregiving.

Concerning to level of psychological stress among family caregivers of children with intellectual disabilities, the present study showed that more than three-fifths of caregivers understudy had severe levels of psychological stress in the pre-program implementation phase, compared to a small minority of them reported severe levels of psychological stress after program implementation. It can be due to the positive effect of psycho-educational program implementation of the learned stress reduction techniques including relaxation training (i.e. deep breathing exercises, lifestyle modifications, progressive muscle relaxation, etc.) that enable them to adjust to the extraordinary sacrifices; and deal with the stress associated with child's care. This study result was supported by **Kilic, Gencdogan, Bag & Arican (2013)**, who found that parents reported a reduction in distress level and small improvements in parenting self-efficacy and coping before implementation of intervention program due to training on stress reduction techniques and relaxation strategies. This study results were also in a harmony with the study

conducted by **Arakkathara, & Bance (2019)**, who explained that there was a significant decrease in reported distress levels following the intervention and an increase in parenting self-efficacy due to the learned stress reduction techniques as guided imagery, deep breathing exercise, and anger management strategies.

About resilience level among family caregivers of children with intellectual disabilities, this study indicated that there was a highly statistically significant difference between total level of resilience among caregivers of children with intellectual disability in the post-program implementation phase compared to the pre-program phase. This could be attributed to social skills training and social support that enable the caregivers to adapt and live with children with intellectual disabilities and positive perceptions of the disease process. This result was supported by **Peer & Hillman (2014)** who noted that social support; open and predictable patterns of communication; a supportive family environment, including commitment and flexibility; family hardiness; internal and external coping strategies; a positive outlook on life; and family belief systems could improve the level of resilience among family caregivers of children with intellectual disabilities.

The current study found that there was an improvement in the mean score of the individual subscale of resilience post-program implementation compared to the pre-program level. It can be attributed to the positive effect of the psycho-educational program implementation on the improvement of resilience and minimizing stress level that enhances the personal satisfaction regarding caring of the child with intellectual disabilities through learning how to master the child's behavioral problems, encouragement of social interaction, spiritual commitment, practicing a healthy lifestyle includes; eating a complete balanced diet, getting a restful sleeping, physical exercise. This study results were in a harmony with the findings of **Jenaro, et al (2020)**, who reported that training of family caregivers of children with intellectual disabilities on mastering child's behavioral problems through establishing daily routines and house rules, positive discipline, practicing

positive behavior management skills, including praise, ignoring, teaching good behaviors, methods for diverting child attention could improve their level of coping and satisfaction and improve their resilience with patient care.

This study indicated that there was a highly statistically significant relation between caregivers' feeling of desire and frustration domain of psychological stress scale and their level of resilience pre-post program implementation. It could be attributed to the improvement reported post-program implementation and acquired coping skills including communication skills that enhanced the relationship between the child and his caregivers, conflict resolution skills, priority setting, and problem-solving skills, seeking social support through integration in a self-help group, and access to the healthcare facilities. these study results were supported by **Feniger-Schaal, & Joels (2018)**, who found that social skills training could minimize the negative feelings associated with the care of patients with mental disabilities such as feelings of depression, loneliness, anxiety, frustration, or despair.

This study also illustrated that there was a statically significant relation between problems of independence performance of the child in psychological stress scale and the family dimension of resilience pre-post program implementation. It can be due to the positive effect of the psycho-educational program that enables the family caregivers to manage the huge effort related to patient care in addition to other duties and responsibilities related to family care e.g., child's hygiene, preparation of food, follow up with health facilities, medication administration, child's protective measures from abuse or injury. Intervention includes skills training on management of child behavioral problems, establishing routines and house rules, positive discipline, practicing positive behavior management skills, including praise, ignoring, teaching good behaviors, methods for diverting child attention. This result was agreed by the findings of **Mohan & Kulkarni, (2018)**, who mentioned that lifestyle modification for family caregivers of children with mental disabilities could minimize their level of stress and improve their coping with

daily life stressors and life demands in addition to child's care burdens.

The findings of this study were also revealed that there was an improvement in the caregiver's Inability to tolerate meeting the child's needs post-program implementation compared to the preprogram phase. It can be due to the learned skills related to **the** management of child behavioral problems, establishing routines and house rules, positive discipline, practicing positive behavior management skills, including praise, ignoring, teaching good behaviors, methods for diverting child attention. This study result was agreed by **Whiting, Nash, Kendall, & Roberts (2019)**, who explained that children with ID have a greater chance of developing behavioral problems that act as challenges placed on their caregivers. So, helping caregivers to know effective behavioral intervention about caring for children with intellectual disabilities, stress reductions measures, and ways to improve resilience could minimize the caregiver's level of psychological stress and improve their resilience.

Conclusions:

- The total level of stress and psychological stress domains has been decreased in the post-program implementation phase compared to the pre-program phase among family caregivers of children with intellectual disabilities.
- A remarkable improvement in the level of resilience has been reported in the post-program implementation phase compared to the pre-program phase among family caregivers of children with mental disabilities.
- There was a highly statistically significant relationship between total level of stress and total level of resilience pre-and post-program implementation among family caregivers understudy.

Recommendations:

- Counseling clinic should be established for all family caregivers caring for children with intellectual disabilities to offer appropriate information and psychological support and guide them to know how to deal with their

child's problems to decrease stress and improve resilience.

- Development of counseling program to all family members to maintain more involvement in caring for children with intellectual disabilities specifically fathers and siblings.
- Conduct a training program for psychiatric and mental health nurses on how to guide family caregivers to help their children with intellectual disabilities to achieve coping and resilience and refer them to the specialized centers that are more able than other healthcare institutions to alleviate the problems, especially as social and psychological experienced by caregivers of children with intellectual disabilities.
- Replicate this study with a much larger sample to ensure consistency with these results and allow for generalizability of the results.

Limitation of the Study:

- It is only conducted in one setting, and results may vary by geographical region. So, this study needs to be conducted in other healthcare centers specialized in caring for children with intellectual disabilities either in rural or urban areas.

References:

- Al-Krenawi, A., Graham, J. R., & Al Gharaibeh, F. (2011).** The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society*, 26(2), 139-150.
- American Academy of Pediatrics (2016):** Committee on Children with Disabilities: Pediatrician's role in the development and implementation of an Individualized Education Plan (IEP) and/or an Individual Family Service Plan (IFSP). *Pediatrics*, 104:124-127.
- Ashori, M., Norouzi, G., & Jalil-Abkenar, S. S. (2019).** The effect of a positive parenting program on mental health in mothers of children with intellectual disability. *Journal of Intellectual Disabilities*, 23(3), 385-396.
- Al-Sartawi, Z. & Al-Shakhs, A. (1998).** Measuring psychological stress, methods of coping, and needs of parents of disabled. Dar Alkutob: Alain, UAE. (PDF) *The Level of Psychological Stress among Parents of Children with Intellectual Disabilities and Slow Learners in Kuwait*. Available from: https://www.researchgate.net/publication/341763481_The_Level_of_Psychological_Stress_among_Parents_of_Children_with_Intellectual_Disabilities_and_Slow_Learners_in_Kuwait
- Alsharaydeh, E. A., Alqudah, M., Lee, R. L. T., & Chan, S. W. C. (2019).** Challenges, coping, and resilience among immigrant parents caring for a child with a disability: An integrative review. *Journal of Nursing Scholarship*, 51(6), 670-679.
- Arakkathara, J. G., & Bance, L. O. (2019).** Promotion of Well-being, Resilience and Stress Management (POWER): An intervention program for mothers of children with intellectual disability: A pilot study. *Indian Journal of Positive Psychology*, 10(4), 294-299.
- Abou-Dagga, S.K (2013).** Psychological Stress and Resilience among Parents of Autistic Children in Gaza Strip. Published Master thesis in Community Mental Health Nursing, Available at: https://iugspace.iugaza.edu.ps/bitstream/handle/20.500.12358/22106/file_1.pdf?sequence=1
- Bhaumik, S., & Alexander, R. (Eds.). (2020).** Oxford textbook of the psychiatry of intellectual disability. Oxford University Press, 1st Edition, pp.35.
- Boat, T. F., Wu, J. T., & National Academies of Sciences, Engineering, and Medicine (NASEM). (2015).** Clinical characteristics of intellectual disabilities. In *Mental disorders and disabilities among low-income children*. National Academies Press (US) published study available at: <https://www.ncbi.nlm.nih.gov/books/NBK332877/>
- Blacher, J., & Baker, B. L. (2019).** Collateral effects of youth disruptive behavior

- disorders on mothers' psychological distress: Adolescents with autism spectrum disorder, intellectual disability, or typical development. *Journal of autism and developmental disorders*, 49(7), 2810-2821.
- Caldwell, J. A., Jones, J. L., Gallus, K. L., & Henry, C. S. (2018).** Empowerment and resilience in families of adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 56(5), 374-388.
- Currie, G., & Szabo, J. (2020).** Social isolation and exclusion: the parents' experience of caring for children with rare neurodevelopmental disorders. *International Journal of Qualitative Studies on Health and Well-Being*, 15(1), 1725362.
- Edition, F. (2013).** Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 21: 591-643
- Feniger-Schaal, R., & Joels, T. (2018).** Attachment quality of children with ID and its link to maternal sensitivity and structuring. *Research in developmental disabilities*, 76, 56-64.
- Hassanzadeh, F., & Hojjati, H. (2017).** The relationship between resilience and care burden among parents of students with intellectual disability in Golestan Province, Iran, in 2016. *Journal of Research in Rehabilitation Sciences*, 12(5), 252-258.
- Henry, C. S., Hubbard, R. L., Struckmeyer, K. M., & Spencer, T. A. (2018).** Family resilience and caregiving. In *Family caregiving* (pp. 1-26). Springer, Cham.
- Hsiao, C. Y. (2014).** Family demands, social support, and family functioning in Taiwanese families rearing children with ID own syndrome. *Journal of Intellectual Disability Research*, 58(6), 549-559.
- Jenaro, C., Flores, N., Gutiérrez-Bermejo, B., Vega, V., Pérez, C., & Cruz, M. (2020).** Parental stress and family quality of life: surveying family members of persons with intellectual disabilities. *International journal of environmental research and public health*, 17(23), 9007.
- Kilic, D., Gencdogan, B., Bag, B., & Arican, D. (2013).** Psychosocial problems and marital adjustments of families caring for a child with intellectual disability. *Sexuality and Disability*, 31(3), 287-296.
- Lee, K., Cascella, M., & Marwaha, R. (2019).** Intellectual disability, pp. 26-30.
- McConnell, D., & Savage, A. (2015).** Stress and resilience among families caring for children with intellectual disability: Expanding the research agenda. *Current developmental disorders reports*, 2(2), 100-109.
- Mohan, R., & Kulkarni, M. (2018).** Resilience in parents of children with intellectual disabilities. *Psychology and Developing Societies*, 30(1), 19-43.
- Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019).** Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in psychology*, 10, 464.
- Oh, S., & Chang, S. J. (2014).** Concept analysis: family resilience. *Open Journal of Nursing*, 4(13), 980.
- Peer, J. W., & Hillman, S. B. (2014).** Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of policy and practice in intellectual disabilities*, 11(2), 92-98.
- Patton, K. A., Ware, R., McPherson, L., Emerson, E., & Lennox, N. (2018).** Parent related stress of male and female caregivers of adolescents with intellectual disabilities and caregivers of children within the general population: A cross-sectional comparison. *Journal of Applied Research in Intellectual Disabilities*, 31(1), 51-61.

Rajan, A. M., & John, R. (2017). Resilience and impact of children's intellectual disability on Indian parents. *Journal of Intellectual Disabilities*, 21(4), 315-324.

Thompson, S. K. (2012). *Sampling* (Vol. 755). John Wiley & Sons.

Wakimizu, R., Fujioka, H., Nishigaki, K., & Matsuzawa, A. (2018). Family empowerment and associated factors in Japanese families raising a child with severe motor and intellectual disabilities. *International Journal of Nursing Sciences*, 5(4), 370-376.

World Health Organization. (2007). *Atlas: Global resources for persons with intellectual disabilities: World Health Organization*, pp. 14-16.

Whiting, M., Nash, A. S., Kendall, S., & Roberts, S. A. (2019). Enhancing resilience and self-efficacy in the parents of children with disabilities and complex health needs. *Primary Health Care Research & Development*, 20(33): 1-7.